American Stroke Association
A Division of American Heart Association

American Heart Association
Learn and Live

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Via Email

Office of Regulations
Social Security Administration
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To whom it may concern:

On behalf of the American Stroke Association (ASA), a division of the American Heart Association (AHA), and over 22.5 million ASA and AHA volunteers and supporters, we submit the following comments in response to the Social Security Administration's (SSA) advanced notice of proposed rulemaking (ANPRM) entitled "Revised Medical Criteria for Evaluating Neurological Impairments (RIN 0960-AF35). [1]"

The American Stroke Association is dedicated to improving stroke prevention, treatment, and rehabilitation through research, education, advocacy and development. Last fiscal year alone, ASA invested more than $162 million on these efforts in activities such as:

- Working with hospitals and hospital systems with treatment of stroke patients, which includes increasing adoption of the ASA's Get with the Guidelines (GWTGs) stroke program[2] — a computerized system designed to improve adherence with our evidence based ischemic stroke treatment and secondary prevention guidelines;

- Collaborating with the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) to develop and implement a voluntary Primary Stroke Center Certification Program[3] to help the general public, Emergency Medical Services (EMS), and healthcare professionals easily recognize which hospitals are optimally equipped and organized to treat patients with acute ischemic stroke.

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[1] 70 Fed. Reg at 19356 (April 13, 2005).

[2] To learn more about GWTG go to:
http://www.strokeassociation.org/presenter.jhtml?identifier=3002728

[3] To learn more about the Primary Stroke Center Certification program go to:
http://www.strokeassociation.org/presenter.jhtml?identifier=3016808

The Primary Stroke Center Certification Program evaluates several nationally recognized performance measures.

- Training EMS professionals on the warning signs of stroke and appropriate response, which includes working at a state level to mandate stroke training and protocol development; and

- Collaborating with the Ad Council in a stroke awareness campaign. The key message for this campaign is to "learn to recognize a stroke and act quickly, because time lost is brain lost." Our public service announcement campaign has raised stroke awareness from 6% to 11%. As a part of this campaign, we are attempting to drive the public to call 911 at the onset of symptoms in order to activate the healthcare system for early intervention and treatment.

ASA efforts extend to the development of clinical practice guidelines and scientific statements designed to advise physicians and other providers on the prevention, treatment and chronic management of stroke,[4] such as *Guidelines for the Early Management of Patients with Ischemic Stroke*.[5] Most recently, the American Stroke Association released its *Recommendations for the Establishment of Stroke Systems Care*, which addresses the entire continuum of care from primordial prevention to rehabilitation.[6]

The ASA commends the Social Security Administration for publishing this advanced notice of proposed rule making. We believe that it is critical to update and revise the neurological rules used by the SSA to evaluate neurological impairments, given that these rules determine who can apply for or receive disability benefits under Title II and the supplemental security income payments under Title XVI of the Act.

Currently, both rule 11.0 and rule 111.0[7] link motor dysfunction with disorganization of motor function for **two extremities**. For example, rule 11.0 defines a central nervous

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[4] To see a complete listing of AHA guidelines, including joint ACC/AHA guidelines go to: http://www.americanheart.org/presenter.jhtml?identifier=3004546

[5] Harold Adams, Robert Adams, Gregory Del Zoppo, and Larry B. Goldstein Guidelines for the Early Management of Patients With Ischemic Stroke: 2005 Guidelines Update A Scientific Statement From the Stroke Council of the American Heart Association/American Stroke Association; Stroke 36: 916-923.

[6] Schwamm LH, Pancioli A, Acker JE 3rd, Goldstein LB, Zorowitz RD, Shephard TJ, Moyer P, Gorman M, Johnston SC, Duncan PW, Gorelick P, Frank J, Stranne SK, Smith R, Federspiel W, Horton KB, Magnis E, Adams RJ; American Stroke Association's Task Force on the Development of Stroke Systems.

Recommendations for the establishment of stroke systems of care: recommendations from the American Stroke Association's Task Force on the Development of Stroke Systems. Stroke 36(3):690-703.

[7] 111.06 defines motor dysfunction due to any neurological disorder as "persistent disorganization or deficit of motor function for age involving two extremities, which (despite prescribed therapy) interferes with age-

vascular accident as "a significant and persistent disorganization of motor function in two extremities, resulting in sustained disturbance of gross and dexterous movements, or gait and stations."

Motor dysfunction can be disabling even with one extremity involved, or with strength not being limited. As an example, a patient with motor dysfunction in one extremity may require assistance for walking or other activities of daily living (ADLs). Also, ataxia may affect the movements of fingers, hands, arms, legs, body, speech or eyes, despite full strength, and can be caused by a number of neurological conditions — including stroke. It can be limited to one extremity in some cases. Other disorders can also affect motor function in a disabling way without necessarily affecting strength. These include choreiform disorders (uncontrollable movements), bradykinesia (often due to Parkinson's syndrome or Parkinsonian-like disorders), cerebellar infarct or degeneration, progressive supranuclear ophthalmoplegia, etc.

Both current rules exclude patients who have dysfunction of only one extremity, irrespective of their inability to function independently and do not account for those dysfunctions that can affect speech and balance. As a result, the rules are currently structured in a way that effectively excludes these individuals from being classified as disabled under Title II and Title XVI of the Social Security Act. Therefore, the ASA strongly recommends that the SSA modify its existing criteria for classifying disability for neurological diseases from "a significant and persistent disorganization of motor function in two extremities" to "a motor dysfunction **in at least one extremity or in any part of the body causing impairment of ADLs**."

The ASA would also ask for clarification on whether "motor disorganization" includes all forms of dysfunction, even where normal muscular strength is preserved (e.g. cerebellar ataxia).

We look forward to working with SSA on this issue. If you need any additional information, please do not hesitate to contact Penelope Solis, J.D. our Regulatory Relations Manager at 202.785.7905 or via email at penelope.solis@heart.org.

Sincerely,

Ellen Magnis

Ellen Magnis
Vice-President
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appropriate major daily activities and results in a disruption of : (a) fine and gross movements; or (b) gait and station."